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ABSTRACT

This study examined states' policies toward families in the context of requirements of Part H of the Individuals with Disabilities Education Act to provide early intervention services to all families with infants and toddlers with special needs. The study reviewed 13 "Year 4" applications for Part H funds from states in all geographical regions of the country and from states with a high percentage of ethnic minorities. Each application was reviewed for general and specific statements of policies aimed at reaching populations typically underserved, and for policies which would empower families by providing them maximum choice and flexibility. Conclusions and recommendations are grouped into the following categories: policies that impact on families' perceptions of problems and needs; policies that enhance enabling factors; policies that empower families; and policies that monitor and support services to minorities. Results indicated that, although all states reflected the spirit of the law, few of the applications had concrete examples or details on how general principles would be put into operations. The 14 specific recommendations include the following: in addition to targeting the general population, public awareness campaigns should also target minority populations; cost of services should be minimized to make these services accessible to all families; Part H should allow families to define their members; and state data systems should include family sociodemographic characteristics to allow monitoring of equitable distribution of resources. (Seven references) (DB)

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Carolina Institute for Child and Family Policy

REVIEW OF STATE POLICIES TO EMPOWER FAMILIES AND REACH POPULATIONS TYPICALLY UNDERSERVED

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SUMMARY

The intent of Part H of the Individuals with Disabilities Education Act (IDEA) is to provide early intervention services to all families with infants and toddlers with special needs, and to do so in a way that recognizes the integrity of families in the care and nurturing of their children. If early intervention services are to be available to all families, and reach families who are typically underserved, policies and procedures must take into account the current realities of the American family (Arcia, Keyes, Gallagher, Herrick, 1992).

In order to examine the states' policies towards families, we reviewed 13 "Year 4" applications for Part H funds. The sample included applications from states in all geographical regions of the country, and from states with a high percentage of ethnic minorities. Each application was reviewed for general and specific statements of policies aimed at reaching populations typically underserved, and for policies which would empower families by providing them maximum choice and flexibility. More specifically, we looked at the following policies:

I. **Policies that Impact on Families' Perceptions of Problems and Needs**

   1. In addition to targeting the general population, public awareness campaigns should also target minority populations.
   2. An extensive child find and referral system should be instituted to reach populations who may be underserved.

II. **Policies That Enhance Enabling Factors**

   1. Cost of services should be minimized to make these services accessible to all families.
   2. Transportation should be provided as needed to ensure that services are accessible.

3. Care for the child receiving services and for young siblings should be provided during meetings with parents as needed to ensure that the lack of sibling care or cost of childcare are not obstacles to parent participation.
4. To ensure that services will be accessible to children whose mothers are in the labor force, it should be possible to provide early intervention services at childcare facilities.

III. **Policies That Empower Families**

1. Part H should allow families to define their members.
2. Part H should allow families to choose the language for meetings, assessments, and services.
3. Families should be able to choose times for meetings and services so as to not interfere with their work schedules.
4. Families should be free to choose their service coordinator.
5. Families should be encouraged to bring a family advocate of their choice to IFSP meetings.

IV. **Policies That Monitor and Support Services to Minorities**

1. State data systems should include family sociodemographic characteristics to allow monitoring of equitable distribution of resources.
2. The lead agency should promote the recruitment and availability of service providers who are ethnically representative of the client population.
3. The lead agency should hire specialists who can provide training, supervision, and technical assistance on issues of cultural sensitivity.

Our results indicate that although all states reflected the spirit of the law, very few of the applications had concrete examples or details on how general principles would be put into operation. There are advantages to broadly stated policies. However, the advantages of clearly worded, family-focused, statewide policies are considerable. They will improve the likelihood that services will be provided to all

families, including those who have typically been underserved. These families will not only be more likely to enter the service system, but they will also be more likely to stay in the system. Therefore, we suggest that state policymakers review their policies with a critical eye for the clarity and specificity necessary to provide wide, properly inclusive coverage.

INTRODUCTION

The intent of Part H of the Individuals with Disabilities Education Act (IDEA) is to provide early intervention services to all families with infants and toddlers with special needs. And to do so in a way that empowers families (i.e. recognizes the integrity of the family in the care and nurturing of their children). In order to make services available to all families, the legislation specifies that a special effort should be made to reach populations who are typically underserved. More specifically, the legislation states as follows.

"Sec. 1478

States shall-

> 7) beginning in fiscal year 1992, provide satisfactory assurance that policies and practices have been adopted to ensure meaningful involvement of traditionally underserved groups, including minority, low-income, and rural families, in the planning and implementation of all the requirements of this part and to ensure that such families have access to culturally competent services within their local areas,"

Examples of policies and practices designed to empower families or reach populations typically underserved have been provided by several researchers and practitioners (Arcia, Keyes, Gallagher, & Herrick, 1992; Burnim, 1990; McGonigel, Kaufmann, & Johnson, 1991; Sonnier, 1991). In this document we report on a set of relevant policies in a sample of state applications for federal funding for Part H of IDEA.

If early intervention services are to be available to all eligible families, and reach families who are typically underserved, policies and procedures must take into account the current realities of the American family. In a study by the Carolina Policy Studies Program, Arcia and associates (Arcia et al., 1992) reported on the nationwide

distribution of some of the family sociodemographic factors that are associated with underutilization of health and social services. Arcia and associates estimated that 54% of children under five have mothers in the labor force, 35% live in families with very low income, and 32% are of ethnic minority. Ten percent of all young children and 20% of young minority children have three or more determinants of underutilization. These children live in families with very low income, with mothers in the labor force, and with at least one additional determinant: large family, mothers with less than a high school education, or mothers who were teen-aged at the birth of the child. In contrast, only 7% of the nation's young children have none of the determinants of underutilization.

A sample of state applications for federal funding for Part H of IDEA was reviewed for policies aimed at making services available to all eligible families. The policies were also reviewed for specificity and concreteness.

METHOD

Sample

Thirteen "Year 4" state applications for federal funding for Part H of IDEA were selected for review. According to statute, the "Year 4" applications must describe state policies for the components of the service system. At least one state was chosen from each of the geographical regions presented in the report by Arcia et al. (1992), to assure that the sample spans the continental United States. In addition, applications were selected to include a sample of the states with the highest percentage of ethnic minority populations, so that in terms of population, the 13 states reviewed included the 6 states with the largest child populations, 1 state with fewer than 100,000 children, and 9 of the 19 states with the highest percentage of ethnic minority children. Overall, the 13 states reviewed have approximately 54% of the nation's total young child population.

Procedure

The second author reviewed all of the applications selected. She searched in each for general and specific statements of policies aimed to empower families, to maximize family participation, and to reach populations that are typically underserved. More specifically, she read the text of each application and appendices searching for policies similar to those suggested by Arcia et al. (1992) and for key words derived from those policies. For example, she searched each application for descriptions of public awareness campaigns, and for any details as to how these might specifically target minority populations. For purposes of validation the first author reviewed 2 of the 13 applications.

RESULTS

There are four types of policies that may facilitate the participation of families who are typically underserved. They are: a) those policies which impact on families' perceptions of their problems and needs, b) those policies that enhance enabling factors, c) those policies that empower families, and d) those policies that specifically monitor and support services to minorities. Following are the results of our review of the state applications, categorized by these four different policies.

Policies that Impact on Families' Perceptions of Problems and Needs

Before entry into the service system can occur, a family must recognize that their child has a developmental problem and that services exist for that problem. Two policies can be adopted to ensure that families of young children are aware of the existence and availability of early intervention services. These are public awareness campaigns, and child find campaigns to inform professionals who may serve as referral sources. Both strategies to reach families in need can be designed with special provisions to target minority populations.

1. In addition to targeting the general population, public awareness campaigns should also target minority populations. In terms of general

public awareness, nearly all the state applications reviewed specified some of the means that Part H would use to increase public awareness of services. Among the strategies listed were: use of logos, fact sheets, pamphlets, brochures, newsletters, news releases, posters, radio, television, and presentations at workshops, conferences, fairs, and special events. Nearly all states have set up a toll-free hotline for parents to call for information. In addition, one lead agency proposed establishing an "Early Intervention Awareness Week," and another has established a Subcommittee for Public Awareness. Places listed in the applications for posting information included day care centers, WIC (Women, Infant and Children) and EPSDT (Early Periodic Screening, Diagnosis and Treatment) centers, clinics, libraries, parent organizations such as the P.T.A., businesses, colleges and universities, and volunteer groups. Two applications specified that information would be made available at churches and/or religious organizations.

We suggest that there are three components to public awareness campaigns for minority populations. First, they must be delivered in the language of the minority group, or in a dialect or mode of communication appropriate for the group. Second, they must be targeted at places or by media used by the minority group. And third, their content must be culturally appropriate for the group.

Several of the applications cited specific strategies to reach minority populations. In terms of appropriate language, five applications recognized the need for campaign materials in languages other than English. Two applications specified that materials which provide information on Part H services would be written in English and "other

languages." One state reported that its Subcommittee for Public Awareness includes Spanish translators.

With regard to places and media used by minority groups, one application reported that the lead agency would distribute information to ethnic radio stations and newspapers. A second application specified that "the public awareness campaign needs to be multimedia, multilingual, multicultural and sensitive to the needs and preferences of people in both rural and urban communities."

Finally, the need for information to be culturally appropriate was cited in two more applications. One state included cultural awareness experts in its Subcommittee for Public Awareness. Another established a Minority Advisory Committee with the explicit goal of including representatives from "various minority groups, including the three largest-- African American, Hispanic, and Asian." The purpose of the committee was to develop a liaison with minority populations who "may have been unserved or underserved by intervention programs in the past and to increase participation in the development of the state plan."

2. An extensive child find and referral system should be instituted to reach populations who may be underserved. If children in need of services are to be referred, it is necessary to provide information on early intervention services to a wide network of service providers, community leaders, clergy, and others who deal with families of young children. Most of the applications we reviewed had a long list of referral sources. The sources included child care programs, local education agencies, hospitals, physicians' offices, public health facilities, other social service and health care facilities, housing authorities and welfare agencies.

One application in particular had a more extensive than usual list of referral sources. It included Migrant Health Programs, Indian Health Service, low income programs in general, domestic violence shelters, family courts, and food pantries.

Policies That Enhance Enabling Factors

Enabling factors are activities or characteristics of the family and of the service sector that make programs accessible and that make the use of services feasible. The major enabling factors are: the ratio of finances available to the family for procuring services to the cost of services, the ratio of time available to the family for services to the time required for services, the availability of the type of services needed in relation to the distance to them, and previous or current contact with the service sector. Strong enabling factors make services feasible for families who would otherwise not be able to consider them. In general, factors that enable the use of services are those that reduce the direct and indirect cost of services, and provide them in a place and at a time that is accessible to families.

1. Cost of services should be minimized to make these services accessible to all families. As required by Part H legislation and regulations, applications specifically stated that inability of the family of an eligible child to pay for services would not result in the denial of services. In addition, four applications specified the set of early intervention services that would be provided at no cost to families as well as other services that would be provided on a sliding scale.
2. Transportation should be provided as needed to ensure that services are accessible. Transportation represents a significant indirect cost of services. However, there was very little mention of transportation in the applications reviewed. One application stated that "transportation is necessary to receive service," and a second application stated that

"families have material needs that may relate to services, including transportation."

3. Care for the child receiving services and for young siblings should be provided during meetings with parents as needed to ensure that the lack of sibling care or cost of childcare are not obstacles to parent participation. None of the applications reviewed specified that the lead agency would arrange for the provision of care for young siblings to facilitate parental involvement.

4. To ensure that services will be accessible to children whose mothers are in the labor force, it should be possible to provide early intervention services at childcare facilities. Nearly all applications indicated that services would be conducted in a setting convenient to families. One of the applications specified that possible settings for meetings or the delivery of services included a family's home, childcare centers, churches, a family resource center or other community buildings.

Policies That Empower Families

The intent of Part H of IDEA is to empower families; its regulations "should have a positive impact on the family, because they strengthen the authority and encourage the increased participation of parents in meeting the early intervention needs of their children" (United States Department of Education, 1989). We suggest that the key feature of empowerment is having a wide range of choices and the freedom to choose.

1. Part H should allow families to define their members. Although applications in general did not contain specific definitions of a family, several applications demonstrated recognition of how cultural diversity affects the definition of what constitutes a family. For example, one application specified that "states and programs should define 'family' in a

way that reflects the diversity of family patterns and structures." One application specified that "each 'family' is able to define itself."

2. Part H should allow families to choose the language for meetings, assessments, and services. Nearly all applications referred to the importance of communicating with children and families in a mode that would not place them at a disadvantage. However, the wording in applications varied between "native language of the parent/family" and "native language of the child." One of the applications recognized the important distinction between native language and language of preference by stating that the Individualized Family Service Plan (IFSP) would be written in the preferred language of the family. Only one application recognized that a child's language of choice may differ from that of his/her family's by specifying that the service coordinator must document the respective primary language of each family member.
3. Families should be able to choose times for meetings and services so as to not interfere with their work schedules. Nearly all applications specified that IFSP meetings should be conducted in a setting and at a time convenient to the family. One application in particular specified that "programs should be flexible, accommodating varying family needs, cultural differences, and family work schedules." Only one application specified that possible meetings included evenings, early morning hours and weekends.
4. Families should be free to choose their service coordinator. The federal regulations specify that service coordinators are to be assigned on the basis of families' needs, and such intent is expressed in all applications. Some of the applications were more specific than others in laying out the procedures whereby families may exercise a choice. One of the

applications stated that "appointment of the service coordination shall be done in consultation with the family," and that "a family can initiate a change in service coordinator at any time by requesting an IFSP review." Another application specified that the initial orientation with families "should include a discussion with the family on the choices of case managers available to them."

5. Families should be encouraged to bring a family advocate of their choice to IFSP meetings. Nearly all applications noted that "IFSP participants may include other family members or child care persons, or an advocate or person outside the family, when requested by the parents." Although families have the right to bring an advocate to IFSP meetings, none of the applications specifically stated that families would be informed of this right. Applications did not specify if advocates would be provided for families desirous of an advocate but unable to secure one themselves.

Policies That Monitor and Support Services to Minorities

Ethnic minorities constitute groups that may need the provision of special policies to ensure that they are not underserved. Depending on the geographical and sociodemographic characteristics of each state, groups who are at risk of being underserved include, among others, families who reside in inner cities or in remote rural areas, those who are homeless, and those with very low income.

1. State data systems should include family sociodemographic characteristics to allow monitoring of equitable distribution of resources. The federal legislation has specified the establishment of statewide data collection systems. Although all state applications reviewed have documented that such systems were being established, the applications did not specify if the data system would or could be used to monitor

equitable distribution of services across populations or geographical areas.

2. The lead agency should promote the recruitment and availability of service providers who are ethnically representative of the client population. A shortage of trained personnel was noted in almost all applications. One application specified the need for more personnel in rural areas, and a second specified the need for more bilingual staff. Another application indicated the need for a "well financed recruitment effort...including a means to... attract personnel who represent diverse social, economic, cultural, and religious backgrounds." No other application specified a policy to recruit ethnic minorities.

3. The lead agency should hire specialists who can provide training, supervision, and technical assistance on issues of cultural sensitivity. The need for services to be culturally sensitive was acknowledged in almost all applications. One application stated that "Early intervention systems and strategies must reflect a respect for the racial, ethnic and cultural diversity of families." The lead agency in that state indicated that it has a training program that includes teaching about "diverse family structures, cultural, linguistic and religious values: and the impact of different social, economic, cultural, linguistic and religious family backgrounds on service delivery."

DISCUSSION

The purpose of this study was to review a sample of Year 4 state applications for policies to empower families and reach populations who have typically been underserved. Overall, there were many statements in the applications that expressed the intent to facilitate services for all families, and to make the services family driven and thus sensitive to individual needs and priorities. The components of public

awareness and child find provided the greatest detail on how states would accomplish their goals. In other areas, however, there was relatively modest specification as to how the intent was to be implemented. Generally only 2 or 3 of the 13 applications reviewed provided concrete details as to how other policies would be implemented.

Definition of policy. Gallagher, Harbin, Eckland & Clifford (in press) define policy as the "rules and standards that are established in order to allocate scarce public resources to meet social needs." Written policies should help us understand who gets the resources, what resources and services will be delivered, who will deliver the services, and the conditions under which services will be delivered (Gallagher et al., in press). The state policies described in the applications generally do not provide the level of detail necessary to understand their intention as thoroughly as suggested by Gallagher et al. (in press).

Advantages and disadvantages of concrete policies. There are advantages and disadvantages to detailed specification of policies. If policies are written vaguely, with phrases such as "services shall be sensitive to cultural differences," or "services will utilize resources in creative and flexible ways that allow for individual and community differences," then freedom of interpretation can be exercised at the local level.

Autonomy, at any level, is one of the most highly valued principles in our society, but freedom of interpretation may include inadequate interpretations. Also, vague policies have phrases to which few can object. Whereas "utilizing resources in creative and flexible ways" will not raise an eyebrow, if an application specifies that it will develop a service delivery program in conjunction with a major church, some may object on the basis of the principle of separation between church and state. Therefore, even though networking through churches is an effective way of reaching some ethnic minorities (Eng & Hatch, 1991), the writers of the applications should refrain from specifying an option that could place their application in jeopardy or delay its approval.

Applications may be jeopardized or delayed because the role of the Office of Special Education (OSEP) is to oversee that state policies are in compliance with the legislation. OSEP therefore reviews with most care applications that appear to depart from the federal regulations.

Limitations of the study. Our review was limited to the materials in the "Year 4" state applications. We cannot report on state procedures, rules or plans not included in the applications and appendices, even though such procedures may exist and be implemented. Nonetheless, we think that the relative lack of detail in the applications is of importance.

Need for well specified written policies at the state level. Written policies are the promises that a state makes to its people. Decisionmakers demonstrate their commitment to policies in two ways: by the degree of precision they use in the wording, and by the type of document in which they place the policies. Policies which are placed in more formal documents such as approved statewide rules and regulations are more binding than policies included in internal plans or guidelines.

For reasons of feasibility there are numerous policies that require development, specification, and implementation at the state level. If these policies are not instituted at the state level, they are beyond the scope of local programs. Policies other than the specific practices associated with the provision of services are beyond the scope of local programs. Policies that should be instituted at the state level include those associated with public awareness and child find campaigns and materials, cost structures for services, the use of materials in languages other than English, organization of data collection systems, and recruiting personnel with special skills or backgrounds. For example, local programs cannot opt to hire ethnic minorities if there aren't any professionals from the relevant ethnic backgrounds. The policy to attract and train ethnic minorities needs to be established at the state or federal level.

A second reason why important policies should be instituted at the state or federal level is that service providers and administrators whose background is service provision cannot be expected to divert funds from the provision of services to projects with long range goals. By training and experience their choice will almost always be to provide immediate and extensive services, particularly to families who are already requesting services. Projects with long term goals must be planned for, and funds must be earmarked, at the state or federal level. The establishment of progressive policies, funding of projects with long-term benefits, and development of a vision that goes beyond the families "at the service door" needs to be carried out at the state and federal level.

Recommendations. Federal agencies can play an important role in motivating and promoting the development of sound, progressive state policies. Although rules, regulations and control are never popular, guidance and good examples are generally welcomed. In addition, OSEP could foster concrete policy specification on the part of the states if it were allowed flexibility in interpreting compliance.

There is a limited number of good ideas, and it is inefficient for all state and local programs to have to discover them independently. Statewide policies can be implemented with minimal restriction of initiative at the local level if systems to exchange information are used extensively. Good exchange of information both within and between states can promote the development of good policies.

We recognize that in many states local autonomy is highly valued and statewide policies are viewed as restrictive. However, we suggest that the advantages of detailed policies make it worthwhile for states to review their written policies critically and to weigh the advantages and disadvantages of making them specific.

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